The Sydney Morning Herald

Medical misogyny

Ella was locked in a psych ward at 19 weeks pregnant, but doctors had misdiagnosed her

By Kate Aubusson

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Ella Rich was 19 weeks pregnant when she was sent to a mental health unit for an undiagnosed drug reaction to medications she was prescribed to treat hyperemesis. BELINDA SOOLE

Depression" was typed in neat black letters next to "reason for presentation" on Ella Rich's discharge summary. It was a confounding diagnosis for the then 33-year-old, who had presented to the emergency department 13 weeks pregnant with severe nausea, vomiting and arms that jerked violently about her, completely beyond her control.

It wasn't the first or last time that Ella was given a mental health diagnosis when she presented to a regional NSW hospital in 2023 with signs of serious movement disorders: uncontrolled and repetitive movements, muscle spasms, tremors, locked jaws, hands clenching and unclenching, and her neck twisting from side to side.

"I was in a state of prolonged distress for months," said Ella, now 35. "I was terrified that my uncontrollable movements would harm my children, my unborn baby or myself … and felt like

no one was listening to me."

From her first presentation, it took the hospital more than 10 weeks to discover that Ella's symptoms were a severe reaction to medications she was prescribed, beginning with a common drug to treat hyperemesis gravidarum (HG), a condition characterised by debilitating nausea or vomiting during pregnancy.

During the ordeal, Ella was involuntarily admitted to the hospital's locked mental health unit, 19 weeks pregnant and traumatised.

The hospital staff came close to identifying the cause earlier. But they wrongly assumed Ella had overdosed on the anti-nausea drug and prescribed a host of new medications, including antipsychotics with a known risk of causing the same movement disorders that Ella exhibited.

"I kept telling them that I thought the drugs were causing my symptoms," Ella said.

This masthead has uncovered a series of disturbing cases where women claim they have been wrongly admitted to mental health wards.

Psychiatry and trauma experts have shared harrowing cases in which clinicians incorrectly concluded that a woman's pain was "all in her head", scuttling attempts to investigate the actual cause, and hundreds of women told this masthead that their symptoms were dismissed as anxiety or depression only to be later diagnosed with serious or life-threatening conditions, including heart attacks, internal bleeding and cancers.

What is HG?

- HG is a condition in pregnancy that starts before 16 weeks' gestation and is characterised by severe nausea and/or vomiting and an inability to eat or drink normally. It strongly limits daily activities.
- An estimated 3 to 10 per cent of pregnancies will be affected by HG.
- The cause of HG remains unclear, but research suggests that hormones are implicated: human chorionic gonadotropin or hCG (which increases rapidly during pregnancy), GDF15 (produced by the fetus and placenta), and oestrogen. Family history and genetics may also play a role.

Ella's case cuts across multiple manifestations of medical misogyny, from the minimisation of HG (a poorly understood and under-researched phenomenon) to women's pain being dismissed in favour of mental health diagnoses that obfuscate the actual, physiological cause of their distress.

What happened to Ella

It's difficult to pinpoint why Ella was dismissed as a mental health case. Was it because her first baby, Tilly, died at just 13 days from a congenital abnormality detected when Ella was 34 weeks

pregnant? Or that Ella had been prescribed an antidepressant, which she took through her two subsequent pregnancies with her daughters, now aged 6 and 3?

Was it her repeated presentations to the hospital with HG and, later, her undiagnosed drug-induced movement disorders, dystonia and dyskinesia? Or that she disclosed to staff the mental distress that her symptoms were causing?

Ella said neither her doctor nor pharmacist mentioned any potential side effects from taking metoclopramide, the generic name for one of the most common drugs prescribed for HG. No side effects were mentioned for any of the subsequent drugs she was prescribed, including antipsychotics, antidepressants and antianxiety medications.

Her nausea was so constant and debilitating that she told several clinicians she had considered terminating her planned pregnancy.

“I didn’t want to terminate, it was just a way of expressing how unwell I was. I felt like no one believed me about the extent of my hyperemesis,” said Ella, recalling some hospital staff telling her that her anxiety was the cause of her HG.

‘Just morning sickness’

Caitlin Kay-Smith, founder of advocacy organisation Hyperemesis Australia, said women’s accounts of their HG were often doubted by their doctors.

“They will say, ‘I am throwing up 10 or 20 times a day’, and they’re told, ‘That can’t be true. How are you sitting in front of me functioning if that were the case?’” Kay-Smith said.

“In emergency departments, women get questions, ‘Do you really need to be here? Are you really throwing up that much?’ Some women have had to beg for IV fluids.

“There’s still this dismissal of HG as ‘just morning sickness’. Something cute and normal.”

Caitlin-Kay Smith, founder of Hyperemesis Australia: "There's still this dismissal of HG as 'just morning sickness'. Something cute and normal." EDWINA PICKLES

HG's psychological toll can be devastating.

Data on the reasons for abortion in Australia is limited, but a 2021 UK survey of 5000 women with HG found 4.9 per cent had terminated wanted pregnancies due to the condition.

Sufferers are more likely to develop perinatal anxiety and depression and post-traumatic stress disorder, Australian research shows.

Misdiagnosed with agitated depression

For Ella, the side effects began almost immediately after starting the metoclopramide. She presented to hospital with her right leg shaking, her face drooping and slurring speech. She told staff that she felt like bugs were crawling over her skin.

"I had started to feel out of my body, restless and irritable. I didn't know what was happening to me, and it was all I could think about," she said.

Hospital staff told Ella she was having a panic attack and prescribed a sedative.

After another presentation, she was diagnosed with "agitated depression".

Ella was rushed to hospital twice suffering severe, seizure-like dystonic attacks. She had no control over her body's violent shudders and was afraid she would asphyxiate as her vocal cords were contracting. She couldn't open her eyes and her neck was wrenched back.

“My husband and mother-in-law thought I was going to die as they watched my limbs kick to the roof uncontrollably and my back and neck spasm,” Ella said of the first episode.

A doctor on ward rounds said words to the effect of “when this was sold to me, I thought ‘pregnancy, anxiety, mental health’ but it’s a classic case of [metoclopramide] toxicity”, Ella recalled, insinuating she had overdosed.

Her medical notes stated, “unintentional dopaminergic [anti-emetic] overuse”, but Ella said she had taken less than the prescribed doses.

“There seemed to be an assumption that I had taken an unintentional overdose because I was anxious and depressed. Case closed,” Ella said. “No one bothered to ask or check how much I’d been taking.”

Associate Professor Luke Grzeskowiak, a clinical pharmacist who also leads the Reproductive and Perinatal Pharmacoepidemiology Research Group at Flinders University, said drug-induced movement disorders were well-recognised side effects of metoclopramide and antipsychotics.

“We are talking one in 100 [people who take metoclopramide] could experience dystonic effects, and it can occur at low doses,” Grzeskowiak said.

“The vast majority will get through without experiencing anything, then there will be a small number with debilitating side effects … and we don’t know why.

“Polypharmacy – adding medications on top of each other – can increase someone’s likelihood of having adverse reactions.”

Dr Debra Kennedy, the director of MotherSafe – a free telephone counselling service for women and their healthcare providers concerned about drug or environmental exposures during pregnancy and breastfeeding – said metoclopramide was a “horrible, crappy drug for HG” prescribed as a first-line treatment at disproportionately high rates by Australian prescribers.

Dr Debra Kennedy, the director of MotherSafe at the Royal Hospital for Women. MAX MASON-HUBERS

“I try to get people off it,” Kennedy said. “It’s not particularly effective, and one of the most common side effects is that it exacerbates depression, which a lot of these women will have associated with the nausea and vomiting.

“The guidelines say you should only prescribe metoclopramide for five days, but no one looks at that … they are happy to prescribe it forever.”

Ella recalled feeling like a medical oddity as the doctor, without speaking directly to her, invited clinicians on ward rounds to “look at this, look at that”, as he pried open her eyelids to reveal

only the whites of her eyes.

She was treated for the "toxicity", diagnosed with depression and prescribed mirtazapine, an antidepressant that also has an antiemetic (nausea and vomiting prevention) effect.

Back home, Ella started having terrible dreams and what she assumed were panic attacks.

She told her GP she felt like running into traffic and was referred for a voluntary admission to a mental health unit for three days. Quetiapine, an antipsychotic, was added to her medication mix. An admission to a private mental health hospital in Sydney followed.

All the while, Ella's dystonic movements continued until they became so distressing that she moved to her parents' home and away from her two small daughters for fear of unintentionally injuring them.

"I kept saying to Mum and Dad that the drugs were doing me harm," Ella said. "I really wanted to die, but it was mostly because of the way I felt physically."

For three days, Ella's involuntary movements were violent, flailing and unremitting. She could not sleep and would scream in overwhelming distress.

Ella tried to grab a knife, but her father and brother forcefully disarmed her.

Medical misogyny: A call for action

The Age and *The Sydney Morning Herald* have launched an investigation into medical misogyny: ingrained, systemic sexism across Australia's healthcare system, medical research and practise.

More than 1800 women shared their experiences as part of our crowd-sourced investigative series, which prompted a national outpouring of grief and frustration as women described feeling gaslit, dismissed or being told their pain was "all in their heads".

We call on the federal government to boost Medicare funding for GP appointments that last more than 20 minutes to improve care for women and others with complex health conditions.

The Albanese government and the Coalition have promised to pour $8.5 billion into Medicare to make GP visits more affordable and improve bulk billing rates, but longer 20-minute appointments will receive a smaller proportional funding increase.

Doctors have warned that these policies could further disadvantage women by continuing to incentivise shorter consultations, which don't give GPs enough time to address menopause, pelvic pain and other women's health issues.

An hour later, Ella had her second terrifying seizure-like episode and was taken by ambulance to hospital. This time, she was scheduled as an involuntary patient under the Mental Health Act.

"I couldn't believe what was happening. I was 19 weeks' pregnant and all of my rights were just taken away," Ella said.

Ella's mother, Jenny Johnson, a former senior nurse manager, said a doctor had medically cleared Ella to be scheduled.

"She didn't gather any history … no one seemed concerned that she had had a repeat of an acute medical episode," Johnson said. "Instead, [as a justification for scheduling Ella] they said words to the effect of, 'It certainly sounds like a dystonic reaction, but it's such a small dose that it's highly unlikely'."

From her hospital bed, Ella found a medical journal article online describing metoclopramide-induced tardive dyskinesia. She recognised her symptoms and sent a screenshot to her mother.

Johnson made a call to REACH, a NSW hospital system allowing patients and families to escalate their concerns. She told the officer that there was something everyone was missing: that Ella's medications were causing her symptoms. But no staff arrived to assess Ella.

Ella Rich was diagnosed with "toxicity" despite the fact she had taken less than the prescribed dose of her medication. BELINDA SOOLE

"It was like Ella was put on this runaway train on the mental health track, and no one recognised what was going on," Johnson said.

"She was dehumanised. The lack of kindness was awful."

Johnson had witnessed the same during her career, recalling a young woman presenting to the emergency department with what would later be diagnosed as a brain tumour but who was initially dismissed as a melodramatic "princess".

Ella was terrified in the involuntary psychiatric ward. She worried she would be attacked by the violent male patients and found the staff threatening.

With a contraband pencil and paper that another patient had snuck into the unit, Ella wrote a list to prove to the doctors that she was compliant and could be released.

Two days after she was sectioned, a psychiatrist walked into Ella's room flanked by six doctors and said, "Did you know you're missing part of your cerebellum?" referring to part of the brain critical for co-ordinating movement and balance.

Ella knew. She had been diagnosed with a congenital condition that affected her cerebellum when she was 14 months old. It was well-documented in her medical notes and evident on a CT scan performed six weeks earlier, after her first seizure-like episode, to rule out stroke.

"He said that this changed everything, and it was possibly the reason I suffered so badly with hyperemesis and why I reacted so badly to the drugs," Ella said. "I was predisposed to a high sensitivity for adverse drug reactions."

Even if the link between Ella's cerebellar issue and the drugs was a rare finding, the fact that other causes weren't considered is what is galling to Ella and her family.

Once again, Ella felt she had become an inhuman exhibit to be prodded and examined in front of the crowd of doctors, as she cried uncontrollably.

The same doctor told her the schedule wouldn't be lifted for another six days.

"I was distraught. I was so desperate to get home to my family," Ella said.

"Why was he happy to leave me in that hideous environment for another six days? Why did no one else, over all of those weeks, link my deteriorating mental health to the physical side effects of the drugs I was being prescribed and taking?"

Her mother again called REACH. This time, the REACH co-ordinator listened and took detailed notes. Ella remembers the co-ordinator returning soon after to tell her the schedule had been lifted and Ella would be transferred to the voluntary mental health unit.

When Ella was reviewed by another psychiatrist the next day, he said words to the effect of: "You have all of these red flags with you coming in and out of mental health institutions. If we had let you out and you had done something, we would have all lost our jobs … How do you feel about that? OK, are we clear?"

"This could have ruined my marriage and my ability to be a mother," Ella said, thankful that her baby, now 11 months, is healthy. "I am going to live with this trauma for the rest of my life."

Hospital apologises for multiple reasons

The hospital's directors of emergency medicine, psychiatry and obstetrics apologised to Ella for multiple fronts during a meeting facilitated by the Health Care Complaints Commission in August 2024, including:

- not picking up her movement disorder on her first presentation to the ED;
- being objectified by staff;
- incorrectly assuming she had overdosed;
- failing to consider that a patient who has had one dystonic reaction could have a second one; and
- not informing her husband that she had been involuntarily treated.

Caitlin Kay-Smith hears echoes of her experience in Ella's case. She came close to being scheduled to a mental health unit when she experienced an adverse reaction to metoclopramide.

"I was lucky that a perinatal psychiatrist whose daughter had HG stepped in, and she said, 'No, give her an IV', and she sent me to the maternity ward instead," Kay-Smith said.

"It's not rare for women taking these drugs and having these types of reactions to describe the agitation as being really anxious, and clinicians aren't connecting the dots."

Kay-Smith said women must be told about these uncommon but serious drug side effects. Dystonia and depression are included in the national HG management guidelines (though not dyskinesia, which has a later onset). But, adherence is patchy, Kay-Smith said.

Meanwhile, a lack of awareness about current medications has led to women being denied treatment and ongoing research into new, safer treatments has been stymied by the spectre of the thalidomide crisis – a drug to treat morning sickness in the 1950s and early 1960s that led to more than 10,000 babies being born with birth defects. Thalidomide had been poorly tested, raced to market and advertised as safe for pregnant women and their babies.

"Thalidomide is the reason people just aren't running drug trials on pregnant women," Kay-Smith said.

Mirtazapine – one of the drugs suspected of exacerbating Ella's reaction but relieving her HG symptoms – is considered experimental and not a first-line treatment, and Kennedy said there was a fair amount of reassuring safety information about the drug.

The crux of the issue for Grzeskowiak is: "How well-informed are women [with HG] about these treatments, why do we have so many treatments with severe side effects, and why is there a lack of development and promotion of newer, safer, more tolerable medications for what is quite a debilitating illness?"

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